Long-Term Care: An Overview

Testimony Before Senate Committee on Finance

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Good morning, Mr. Chairman and Members of the Committee. My name is Carol O'Shaughnessy. I am a Specialist in Social Legislation at the Congressional Research Service.

This morning I will provide an overview of long-term care for the elderly and persons with disabilities. I will briefly describe the need for long-term care services, and the role of families and federal programs in providing care.

Defining the Need for Long-Term Care Services

Long-term care refers to a wide range of supportive and health services for persons who have lost the capacity for self-care due to illness, frailty, or a disabling condition. Need for long-term care services is measured by the need for assistance from others in performing basic daily activities, referred to as *activities of daily living* (ADLs) and *instrumental activities of daily living* (IADLs). ADLs are basic human functions, and include bathing, dressing, getting around inside the home, toileting, and eating. IADLs are tasks necessary for independent community living, such as shopping, light housework, and meal preparation.

Legislation to finance long-term care services frequently limits eligibility to persons having limitations in a specific number of ADLs, and, for the cognitively impaired, persons with a similar level of disability. This approach allows policymakers to target people with greatest need and to control costs. Long-term care insurance policies, a limited but growing market, also use ADL limitations to trigger payment of benefits.

Long-term care services include a continuum of health and social services, ranging from care in nursing homes (which averages over $40,000 per year) to care at home through home health and homemaker services, and services in the community, such as adult day care. Long-term care may also be provided in a variety of other settings that provide health and supportive services along with housing, such as intermediate care facilities for the mentally-retarded (ICFs/MR), assisted living, and board and care facilities.

The Long Term Care Population.[1] About 9 million persons over age 18 receive long-term care assistance. The vast majority – over 80% – of these persons are in home- and community-based settings, *not* in nursing homes. Only about 1.6 million persons – less than 20% of all adults receiving assistance – reside in nursing homes.

Persons age 65 and older represent about 60% of all adults who receive assistance (almost 4 million persons in community settings and about 1.4 million of the 1.6 million persons in nursing homes). But the need for long-term care affects persons of all ages. Of the 9 million persons receiving long-term care assistance, about 3.5 million are adults under the age of 65. In addition, almost 500,000 children living in the community have difficulty performing activities of daily living.

About one quarter of adults of all ages who receive care at home and through community services settings have **severe** impairments – that is, they need assistance with three or more activities of daily living. Without home and community support, these persons might require care in nursing homes.

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[1]Data for this section come from an analysis of the 1994 Disability Supplement to the National Health Interview Survey (NHIS) and the National Long-Term Care Survey, *The Characteristics of Long-Term Care Users*, prepared for the Committee on Improving Quality of Long-Tem Care, Institute on Medicine, by William D. Spector, et.al., 1998. These surveys contain the most recent national data on long-term care.

Estimates of the number of persons who need long-term care vary depending upon the number and types of ADL and IADL limitations and other factors used for measurement. Therefore, other research may show slightly different estimates.

In addition, about half of adults of all ages who receive assistance in the community have diminished ability to carry out tasks necessary for independent community living.

The likelihood of receiving long-term care assistance increases dramatically with age. Over half of persons age 85 and older receive long-term care assistance, either in community settings or in nursing homes, compared to only 12% of persons age 65-84. However, regardless of age, older persons are more likely to receive long-term care at home or through community services, rather than in nursing homes. (**Chart 1** on page 9)

Future Demand. The need for long-term care is expected to grow substantially in the future, straining both public and private financial resources. Growth in demand will be driven by large increases in the elderly population as a result of the aging of the baby boom generation and general increases in longevity throughout the population. Estimates show that the number of elderly persons alone who need long-term care assistance could grow by 24% over the next 20 years, and by 75% over the next 40 years. (**Chart 2** on page 10)

While estimates vary, increases in longevity and in the number of older persons are certain to affect the demand for services. Rapid growth in the number of people over age 85 presents special challenges because the "old-old" have the greatest risk of needing care. The demand for home and community-based services may also grow due to the recent Supreme Court decision in *Olmstead v. L.C.* and advocacy efforts of younger persons with disabilities.[2]

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[2]In *Olmstead*, the Court held that Title II of the Americans with Disabilities Act (ADA) requires states to place individuals with mental disabilities in community settings rather than in institutions, when the state's treatment professionals have determined that community placement is appropriate, community placement is not opposed by the individual with a disability, and the placement can be reasonably accommodated. The scope of the *Olmstead* decision applies broadly to all individuals with disabilities protected by Title II the ADA.

Over the last decade, national research on the long-term care population has documented a rather marked increase in the disability levels of persons who receive help. Increases in disability levels have been noted among those who receive assistance at home and through community services, but especially among nursing home residents. Over 80% of nursing home residents have severe impairments, needing assistance with three or more activities of daily living. These trends have implications for caring for very disabled family members at home, as well as for demands on the home care and nursing home workforce.

The Role of Federal Programs and Families

National Spending. The Nation spent $133.8 billion on long-term care for persons of all ages in FY1999. This represents almost 13% of total personal health spending and an amount slightly more than the Nation's spending on prescription drugs and nondurable medical supplies combined. (**Chart 3** on page 11)

Of total national spending on long-term care, Medicaid and out-of-pocket spending represented the two major sources of payment, 44% and 25%, respectively. Medicare plays a smaller role, representing only 14% of total long-term care spending. Private health insurance represented about 10% of the total. (**Chart 4** on page 12)

Role of Families and Informal Supports. Despite substantial public spending for long-term care, families provide the majority of long-term care services. About 37 million caregivers provide informal, or unpaid care to family members of all ages. Typically, this care is provided by adult children to elderly parents and by spouses to one another.

The role of families and other informal caregivers is considerable. Almost 60% of the functionally impaired elderly, and nearly three-quarters of adults under age 65, receiving care rely *exclusively* on informal, unpaid assistance. (**Chart 5** on page 13 displays caregiver patterns for persons 65

and older.) Research has documented the enormous responsibilities that families face in caring for relatives who have significant impairments. For example, caregivers of the elderly with functional limitations provide an average of 20 hours of unpaid help each week. Some estimates have shown that unpaid work, if replaced by paid home care, would cost an estimated $45 billion to $94 billion annually.[3] Some estimates have placed the economic value of caregiving even higher.[4]

Many have argued that while public programs should not and cannot replace family caregiving, targeted initiatives to assist family caregivers are needed. For example, last year Congress enacted the National Family Caregiver Support Program as part of the Older Americans Act. The intent of the program, funded at $125 million this year, is to provide information, assistance, and respite care services to families in their caregiving efforts.

Federal Programs. A number of federal programs directly or indirectly support a wide range of long-term care services. None focus exclusively on long-term care. Eligibility requirements, services authorized, and administrative structures vary among the programs, making coordination difficult. (**Chart 6** on page 14)

- *Medicaid* provides coverage for nursing home care and a wide range of home- and community-based services for persons of all ages who meet income, asset, and categorical eligibility criteria prescribed by federal and state law. Many people qualify for Medicaid benefits not by being poor, but rather, by depleting most of their assets and income to pay for care.
- *Medicare* pays for medically necessary, part-time skilled nursing and rehabilitation therapy services at home; it also pays for up to 100 days of care in a skilled nursing facility following hospitalization for

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[3]Doty, Pamela. *Caregiving: Compassion in Action*. U.S. Department of Health and Human Services, 1998. p. 13. This estimate is based on elderly persons who need assistance with ADL or IADL limitations.

[4]Arno, Peter, et. al. The Economic Value of Informal Caregiving. *Health Affairs*, March/April 1999.

individuals who need full-time skilled nursing care. Medicare does **not** cover long-term care services for persons with chronic care needs or who require only assistance with ADLs.

- The *Social Services Block Grant (SSBG)* program provides a range of home and community-based services to low-income persons of all ages who meet state-defined eligibility requirements. Home care services must compete with a variety of other services for funding.
- The *Older Americans Act (OAA)* supports home and community-based services to persons aged 60 and over.
- *Tax benefits* for long-term care include a limited deduction for long-term care expenses and insurance premiums (provided the taxpayer itemizes deductions), tax-exempt insurance benefits, and the dependent care tax credit.

Other federal programs, such as state supplements to *Supplemental Security Income (SSI)*, support a range of home- and community-based services for persons with long-term care needs. Federal programs or benefits that support persons with disabilities or their caregivers include the *Family and Medical Leave Act* and the *Senior Companion Program (SCP)* which supports volunteer assistance to frail older persons; and various targeted state grant programs such as *Public Health Service* demonstration grants to develop model services programs for persons with Alzheimer's disease. The *Department of Veterans Affairs (DVA)* provides a wide range of long-term care to the Nation's veterans, including nursing home, domiciliary, home health care, and assistance to caregivers.

Despite the range of federal programs and benefits that exist, many observers believe that federal programs do not significantly support the care most people want, that is, home and community-based services. They argue that the current system is flawed because of an over-reliance on institutional care and the sometimes poor quality of such care, the heavy reliance on informal caregivers who bear most of the burden of care, and the uneven availability of home and community-based services that most people prefer over care in institutions.

The Heavy Reliance on Medicaid. While only a small proportion of those receiving long-term care services reside in nursing homes, public spending for nursing home care, primarily through Medicaid, is disproportionately high. Of total Medicaid spending on long-term care in FY1998 ($61.9 billion), almost three-quarters was for nursing home care and care in intermediate care facilities for the mentally retarded; about one-quarter was for home- and community-based care. (**Chart 7** on page 15)

Although nursing home care still dominates Medicaid spending, a shift toward home and community-based care has occurred over the last decade primarily as a result of states' initiatives to provide these services under waiver authority granted by the Department of Health and Human Services under Section 1915(c) of the Medicaid statute. From 1990 to 1998, the rate of increase in Medicaid spending for home and community-based services has outpaced the rate of increase in spending for nursing home care.[5] Also, nursing home spending has decreased as a share of total long-term care spending and of total Medicaid spending over the same period.[6]

Many states consider their Medicaid home and community-based waiver programs as key components in developing long-term care systems. Despite its rapid growth, however, many analysts consider these programs to be only a partial step in providing comprehensive long-term care services because of restrictions on eligibility and limitations in service availability throughout the Nation.

Future Directions

Congress has chosen an incremental approach to changing the federal role in long-term care. Proposals have included both incremental and large

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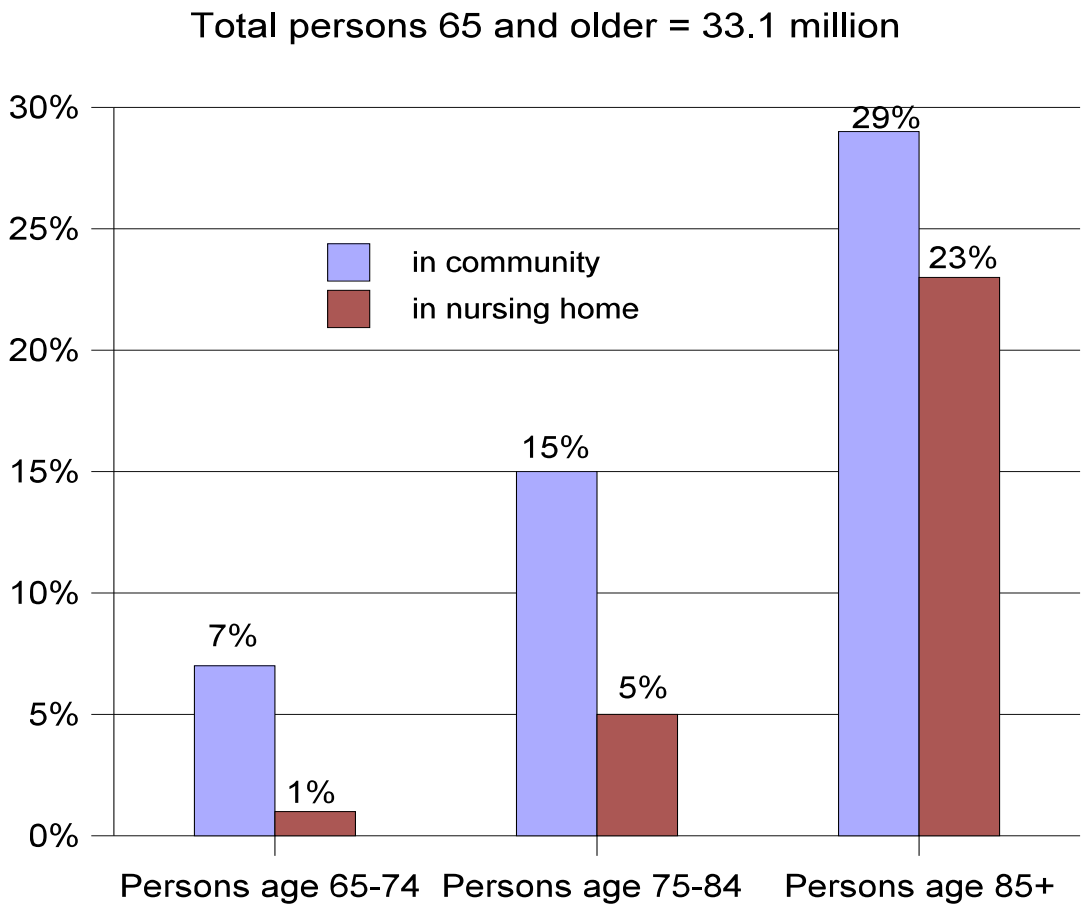
[5]Spending for home and community-based care increased by more than 280%, from $ 4.1 billion in FY1990 to $15.7 billion in FY1998, while spending for nursing home and ICF/MR care increased by 70%, from $26.0 billion to $44.3 billion.

[6]Medicaid nursing home spending declined from 61% to 56% of Medicaid long-term care spending from 1990 to 1998. As a percent of total Medicaid spending it declined from 86% to 71%.

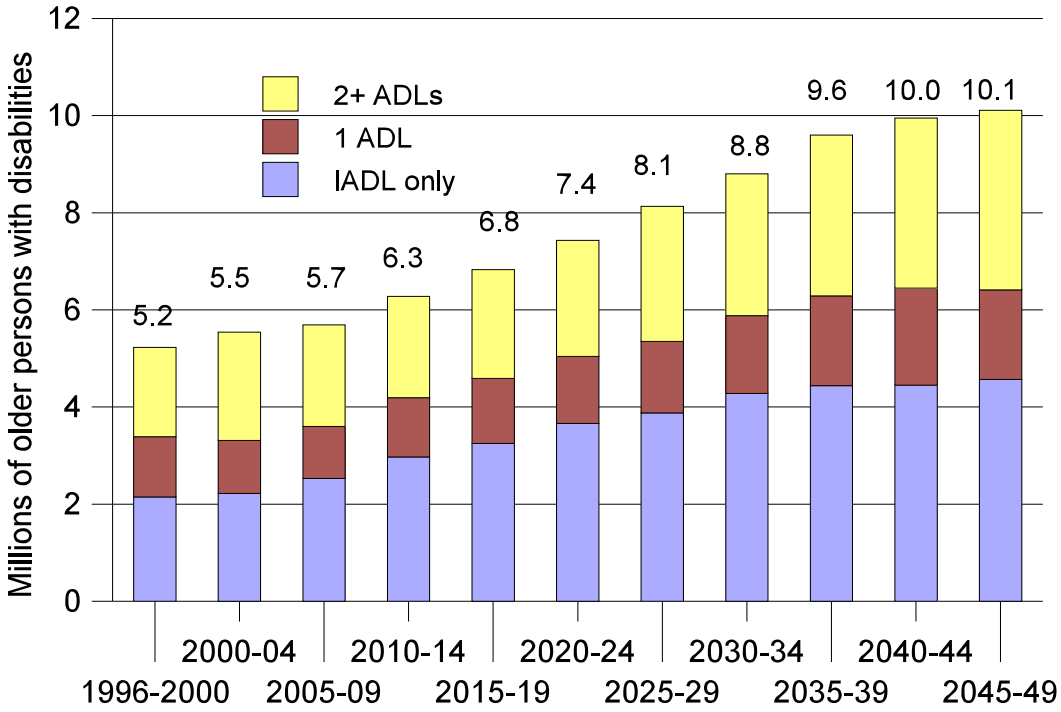
scale approaches. Among the proposals advanced are tax credits for persons with long-term care needs, incentives for private financing through tax deductions for the costs of long-term care insurance, an additional personal exemption for caregivers, and combinations of these. Other broad approaches have included proposals for large scale grants for home and community-based care, social insurance coverage for long-term care costs, as well as expansion of current home and community-based services to cover the entire population in need. A significant challenge for policymakers is to reconcile the concerns about the costs of these proposals as well as the relative roles of the public and private sectors.

Chart 1. Persons Age 65 and Older Receiving Long-Term Care Assistance, By Age and Setting, 1994



Source: 1994 National Long-Term Care Survey from W. Spector, et. al. *Characteristics of Long-Term Care Users.* Prepared for the Committee on Improving Quality in Long-Term Care, Institute of Medicine, 1998.

Chart 2. Projected Growth of the Long-Term Care Population, Age 65 and Older

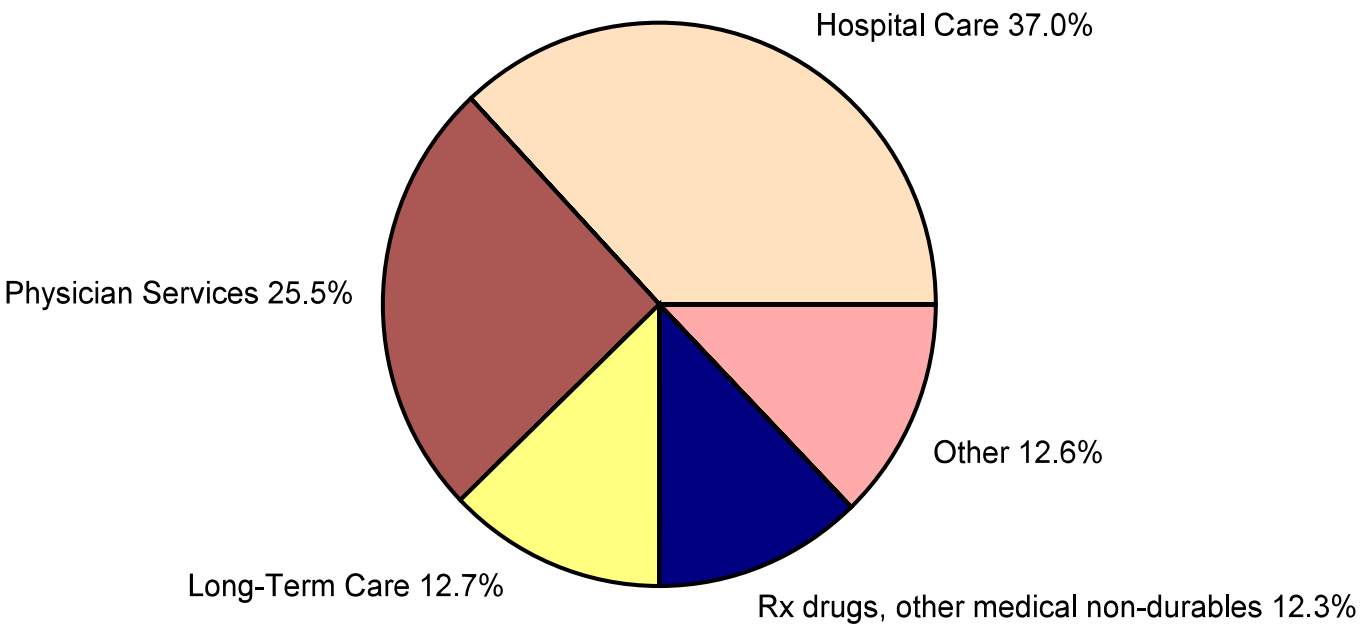


Source: *The Long-Term Care Financing Model*. Prepared by the Levin Group, Inc. for DHHS, 2000. The projected number of older persons with disabilities represents the average for each time period.

ADLs = activities of daily living
IADLs = instrumental activities of daily living

Chart 3. Long-Term Care Spending as a Share of Total Personal Health Care Spending for All Ages, 1999

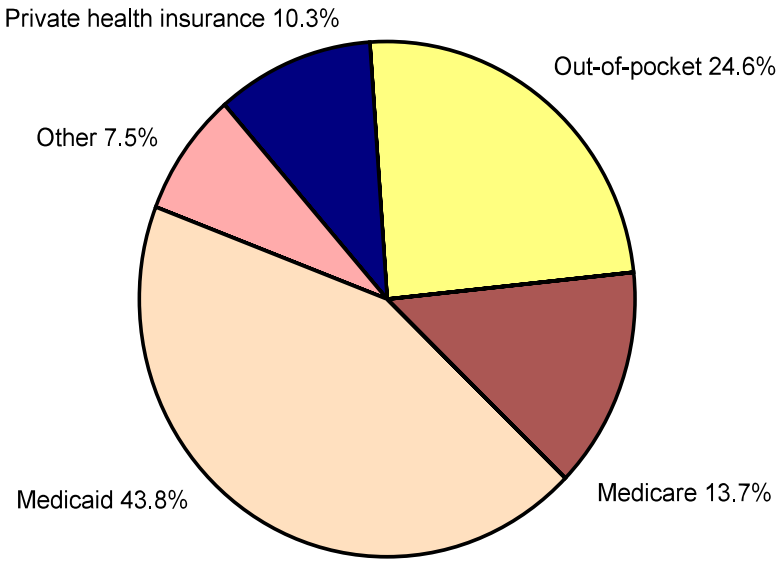
Total personal health care spending = $1.06 trillion



Source: Health Care Financing Administration, Office of the Actuary, National Health Statistics Group.
Note: Percentages do not sum to 100% due to rounding.

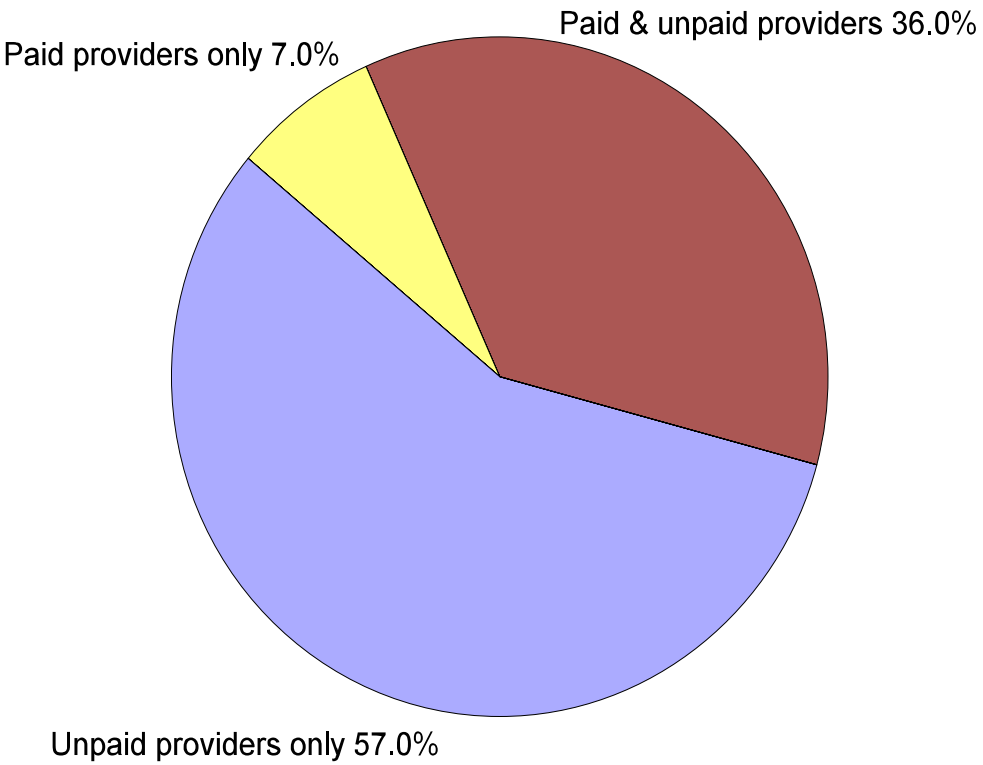
Chart 4. Sources of Long-Term Care Funding, 1999

Total long-term care spending = $133.8 billion



Source: Health Care Financing Administration, Office of the Actuary, National Health Statistics Group.
Note: Percentages do not sum to 100% due to rounding. Medicaid includes expenditures for nursing homes, ICFs-MR, home health, and home and community-based waiver services.

Chart 5. Percent of Persons Age 65 and Older Receiving Long-Term Care Assistance in the Community, 1994



Source: 1994 NHIS-DS, from W. Spector, et. al. *Characteristics of Long-Term Care Users.* Prepared for the Committee on Improving Quality in Long-Term Care, Institute of Medicine, 1998.

Chart 6. Selected Federal Programs for Persons with Disabilities

Medicaid
- *Eligibility*: Children and adults who are blind, disabled, and/or age 65 and older who meet income and asset tests
- *Services:* Nursing facility, home health, personal care services, and adult day care
- *Administration*: State

Medicaid Home and Community-Based Service Waivers
- *Eligibility*: Children and adults who are blind, disabled, and/or age 65 and older who meet income and asset tests, and who would otherwise be in an institution
- *Services*: A wide array of non-medical support services excluding room and board
- *Administration*: State

Medicare
- *Eligibility*: Persons age 65 and older and certain younger persons with disabilities
- *Services*: Short-term skilled nursing facility and home health care
- *Administration*: Federal

Social Services Block Grant
- *Eligibility*: Determined by states
- *Services*: A wide array of home and community-based services
- *Administration*: State

Older Americans Act of 1965
- *Eligibility*: Persons age 60 and older
- *Services*: Nutrition, home care, adult day, respite, transportation, and preventive health services, among others
- *Administration*: State

Supplemental Security Income (SSI) State Supplemental Program
- *Eligibility*: Children and adults who are blind, disabled, and/or age 65 and older who meet state income and asset tests
- *Services*: Cash payments may be used by beneficiaries for home and community care
- *Administration*: State

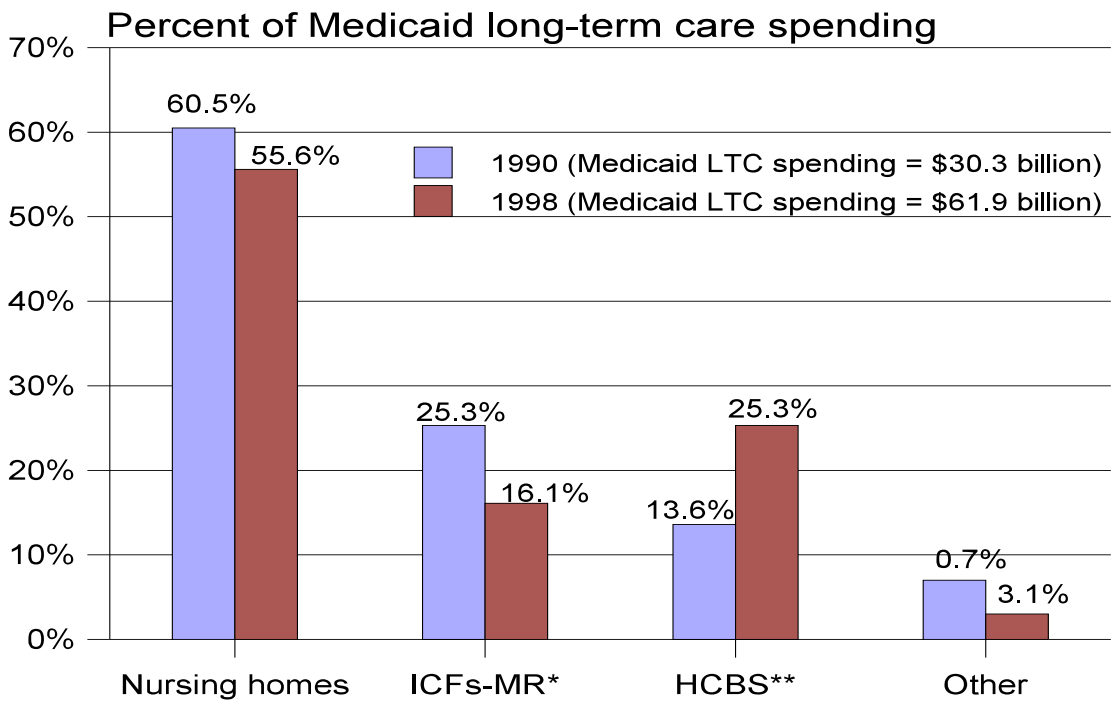
Rehabilitation Act of 1973
- *Eligibility*: Adults who have a physical or mental impairment that results in a substantial impediment to employment and who can benefit from vocational rehabilitation (VR) services
- *Services:* Vocational rehabilitation, employment training, education, and independent living services among others
- *Administration*: State

Supportive Housing (Sections 202, 811) and Congregate Housing Services Act of 1978
- *Eligibility*: Certain adults with disabilities
- *Services*: A variety of supportive housing options
- *Administration*: Federal

Department of Veterans Affairs (DVA)
- *Eligibility*: Based on statutory priorities, including service-connected disabilities and/or income other factors
- *Services*: A range of institutional, residential, and supportive services
- *Administration*: Federal

Percent

Chart 7. Medicaid Spending for Long-Term Care, 1990 and 1998



Source: Urban Institute, based on data from HCFA-64 reports.
Note: Percentages do not sum to 100% due to rounding.
*Intermediate care facilities for the mentally retarded.
**Home and Community-Based Services.